

Assisted Suicide (Scotland) Bill

Inclusion Scotland

1 Background

- 1.1** Inclusion Scotland is a network of disabled peoples' organisations and individual disabled people. Our main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people's everyday lives and to encourage a wider understanding of those issues throughout Scotland.
- 1.2** Inclusion Scotland acknowledges that disabled people are divided on the issue of assisted suicide. We accept that there are disabled people with sincerely held contrary views. However when we last consulted on this issue our membership overall remained against the principle of assisted dying/suicide.
- 1.3** This submission concentrates on two key questions – the General Purpose of the Bill and provision requiring the person seeking assisted suicide to have a terminal or life shortening condition. Answers to the Committee other questions are contained in an annex.

2 Bill's General Purpose: Do you agree with the general purpose of the Bill to make it permissible, in the circumstances provided for, to assist another to commit suicide?

- 2.1** At the heart of the Bill lies a fundamental misunderstanding of the impact of impairment on quality of life. Quality of life (and prospects for its improvement) is not necessarily attributable to any medical condition, no matter how severe or limiting. It is also contingent on many external factors, including public attitudes towards disability (the stigma, misplaced assumptions, hostility and hate crime that disabled people experience), the availability and quality of support and the degree of choice and control that a person has over how they are directed, and the accessibility of buildings, transport and so on that determine whether a person with an impairment is able to participate in society as an equal citizen.
- 2.2** Faced with the prospect of being branded a burden, ostracised and isolated as a social pariah, of a future blighted by poverty, humiliating assessment procedures, vulnerability to abuse and the removal of choice, autonomy and freedom, any rational person might question the value of continuing such an existence. Yet these are not the inevitable outcomes of a medical condition, however defined. They are outcomes of inadequately funded and poorly designed public policy, of a culture that values human life only in financial terms - how much money a person has or can generate, versus how much it costs to ensure a person's quality of life and respect their human rights.

- 2.3** To give people dignity, choice and control over the manner of their death when you have denied them the support they need to have dignity, choice and control over their lives is to play into the hands of any government (at any time) that values profit more than people; that garners support for cuts to publicly funded benefits and services by demonising and dehumanising those who need them. Moreover, ‘those who need them’ are not some small separate sub-set of the population. It might be you tomorrow and will probably be all of us in future, as we approach the end of our natural lives. Surely there should be pressure on governments to ensure provision is in place to make life as good as possible for as long as possible, and that they should be held to account when their failure to do so renders the lives of some of their citizens so intolerable that death becomes the rationally preferred option.
- 2.4** Inclusion Scotland therefore believes it is very dangerous for government to give priority to enabling people who have impairments to have a (debatably) good death rather than to supporting them to have the best possible life. Evidence of current failures regarding the latter is widespread and overwhelming, when it comes to the impact of benefit cuts, social care cuts and negative attitudes.

3 Impact of Welfare Reform

- 3.1** Disabled people and their families are currently being subjected to more than 50% of the £23 billion in benefit cuts imposed via the Coalition Government’s Welfare Reform programme. This will deepen and widen disabled people’s existing poverty. Some disabled people exposed to these cuts have already taken their own lives.
- 3.2** In 2012 the website Calum’s Listi collated the stories of 21 people who had committed suicide as a result of hardship caused by welfare reforms. The fully-referenced list comprised of 21 cases where either a suicide note or the testimony of family or health professionals cited an aspect of the welfare reforms as the main cause for the suicide.
- 3.3** There have been many more such suicides since Calum’s List was originally compiled. The Mental Welfare Commission for Scotland recently published a report on the suicide of a woman with severe mental health issues who had her benefits taken away after a Work Capability Assessment. The Commission heavily criticised the current Assessment regime’s impact on people with mental health issues. The Commission also surveyed 56 psychiatrists who had treated patients who had undergone Work Capability Assessments. To quote the report

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“40% (had at least one patient who had self-harmed after the WCA. 13% (7) of respondents reported that a patient had attempted suicide and 4% (two RMOs) stated that a patient had taken his/her own life”

- 3.4** A Freedom of Information response from 2013 also shows that 58%ⁱⁱⁱ of those subjected to ESA sanctions had mental health issues and/or learning difficulties suggesting that those most vulnerable to self-harm and suicide are also most likely to be subjected to sanctions on their benefit entitlement.

4 Impact of Social Care Cuts

- 4.1** The austerity cuts imposed by the UK Government combined with growing demand for care services (as people live longer) has resulted in the rationing of support which would enable disabled people to exercise choice and control whilst maintaining their dignity. Learning Disability Alliance Scotland estimate that 20,000 disabled people^{iv} who would have qualified for care services 5 years ago are now going without them due to local authorities raising eligibility criteria.
- 4.2** In addition to those that have totally lost their care support many other disabled people have had their care support reduced. Local authorities are increasingly turning to 15 minute visits as a means of satisfying their duty to supply care services. A Unison Scotland FOI request showed that at least 28 Scottish councils commission such short visits^v. Needless to say whilst such visits might meet disabled people's need for "life & limb" cover, and potentially ensure their safety, they seldom enable them to participate in work or wider community life.
- 4.3** Simply being in receipt of care services, even by way of direct payments, does not guarantee a disabled person's right to dignity and respect. In 2009 Ms Elaine McDonald, a former prima ballerina with Scottish Ballet, had who suffered had a life-altering stroke had her care needs re-assessed by her local authority (Kensington & Chelsea). They decided that she should no longer receive payments allowing her to employ overnight care workers instead she would be placed in incontinence pads for ten hours each night, only having them removed the following morning.

5 Right to Dignity

- 5.1** As Ms McDonald believed that lying in her own excrement for up to ten hours at a time effectively removed her right to dignity and respect under the European Convention she took the Council to court. Ultimately, the European Court of Human Rights^{vi} decided that although her right to dignity had been breached the local authority had eventually discharged its duty to take her human rights into account and on balance it was within their wide discretion to reduce her care support in order to achieve savings that would benefit the "wider community".
- 5.2** Thus disabled people have no absolute right to obtain dignity and respect for their needs at present as they are limited by national and local government's discretion to achieve budget cuts. Nearly all

research studies conducted on assisted dying show "not wanting to be a burden" as the principal reason for seeking death. Other disabled people may conclude that life is simply not worth living if they are so poor that they cannot afford to eat (as in the tragic case of Mark Woodvii) or heat their homes or keep a roof over their heads (as a consequence of the Bedroom Tax and changes to Local Housing Allowance).

5.3

6 Negative Attitudes and Stigmatisation

6.1 Finally there are the terms of the debate around Welfare Reform and how this impacts both on public attitudes and disabled people's attitude towards themselves. The Paralympics were thought to have had a positive impact on public attitudes towards disabled people but this appears to have been transitory at best. A survey of 1,014 disabled adults by Scope found that nearly **25%** of those living in London has suffered hostile/threatening behaviour or been physically assaulted since the Paralympics. Across the UK, **17%** of disabled people said they had been attacked. Overall some 81% said they had experienced no improvement in the attitudes shown towards them, while more than one in five of these said behaviour towards them had instead deteriorated since the Games.

6.2 These findings are in line with those of the Glasgow Media Group who carried out research on media coverage of disability in 2011viii. That research found –

- A significant increase in the use of pejorative language to describe disabled people. The use of terms such as 'scrounger', 'cheat' and 'skiver' was found in 18% of articles which mentioned disabled people in 2010/11
- An increase in articles portrayal disabled people as a 'burden' on the economy – with some articles even blaming the recession on incapacity benefit claimants.

6.3 Because of the discrimination, harassment and social isolation that disabled people experience – which Welfare Reform and the rhetoric surrounding it is intensifying – they are much more prone to depression than non-disabled people. Disabled people with a single impairment are two to three times more likely to develop depression than the rest of the population whilst people with three or more impairments or health conditions are seven times more likely to have depressionix

7 Do you have any comment on the provisions requiring that the person seeking assisted suicide must have a terminal or life-shortening illness, or a progressive condition which is either terminal or life-shortening?

7.1 The Bill aims to extend the "right" of Assisted Suicide to those with a

terminal or life-shortening illness or a progressive condition which are terminal or life shortening. This means that the “beneficiaries” of any rights contained in the Bill are restricted to disabled people (The Equality Act defines a disabled person as a person with ‘a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.’)

- 7.2** Everyone in Scottish society has a progressive condition which is terminal or life shortening – it is called aging! Moreover a very large number of conditions which are in not in any way life threatening can nevertheless be life shortening.
- 7.3** For example, approximately 250,000 Scots have clinically significant depression at any one time, and depression was the commonest reason for Scots visiting their GP in 2012. Depression is also known to be a contributor to shorter life expectancy. Those with a learning impairment are also known to have significantly shorter life expectancies (on average 20 years less) than non-disabled people.
- 7.4** In fact the great majority of the 350,000 Scots on Disability Living Allowance would qualify for Assisted Suicide using the broad parameters of having either a terminal or life shortening illness or condition. Even conditions such as blindness or deafness that are not in themselves threats to health can be accompanied by social isolation that can indeed have that consequence.

8 Conclusion

- 8.1** Inclusion Scotland believes that much more needs to be done to ensure that disabled people are supported to live with dignity and respect before we would feel able to endorse the idea of legislating to allow disabled people to be assisted in taking their own lives.
- 8.2** Inclusion Scotland also believes that legalising the assisted suicide of disabled people would allow the State to avoid its responsibility to ensure that disabled people have an adequate income and access to care services. If this Bill succeeds, Inclusion Scotland predicts that disabled people’s despair at their increasing poverty and loss of care support will lead many to choose suicide as an option. Is Parliament prepared to endorse that choice for those reasons?

8.3

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ⁱ “Welfare reform suicides must not be overlooked”, New Statesman, 4/7/12

ⁱⁱ Who benefits? The benefits assessment and death of Ms DE, Mental Welfare Commission for Scotland, March 2014

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- iii See Freedom of Information request –
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/295384/foi-79-2014.pdf
- iv 20,000 LOSE OUT: 1 in 7 lose Social Care Due To Changing Eligibility For Support Services in Scotland, Learning Disability Alliance Scotland, March 2014
- v See here - <http://www.unison-scotland.org.uk/news/2013/julaug/0108.htm>
- vi See here - <http://disabilitynewsservice.com/2014/05/overnight-care-ruling-is-attack-on-rights-say-outraged-campaigners/>
- vii See here - <http://www.theguardian.com/society/2014/feb/28/man-starved-to-death-after-benefits-cut>
- viii Bad News for Disabled People, Glasgow Media Group for Inclusion London, 2011
- ix Investing in emotional and psychological wellbeing for patients with long-term conditions (p.3), Mental Health Network, NHS Confederation, 2012

ANNEX: Summary of responses to Committee Questions

- 1. Do you agree with the general purpose of the Bill to make it permissible, in the circumstances provided for, to assist another to commit suicide?**

For reasons outlined in our main submission, Inclusion Scotland does not support the general purpose of the Bill.

- 2. Do you have any views on how the provisions in this Bill compare with those from the previous End of Life Assistance (Scotland) Bill?**

Whilst the original Member in Charge of the Bill clearly attempted to address some of the concerns raised by Inclusion Scotland and others in response to the End of Life Assistance (Scotland) Bill by redefining the criteria, our fundamental objections remain unaddressed. The previous Bill was criticised for inappropriately targeting disabled people. This one still does. Similarly, while it may contain a statement that the assistance authorised does not include any form of euthanasia, in practice this could be hugely problematic to establish.

- 3. The Bill precludes any criminal and civil liability for those providing assistance, providing the processes and requirements set out in the Bill have been adhered to. Do you wish to make any comment on this?**

In fact it does not appear necessary to adhere to those processes and requirements. Section 24 of the Bill provides that those concerned were acting 'in good faith' and meaning to follow the requirements of the Act shall not be held criminally or civilly liable for incorrect statements, failure to follow those requirements (including omissions) – unless shown to be 'careless'. 24 (3) appears to go further, allowing that nothing done by a person acting in 'good faith' and 'intended adherence to the Act' is affected by any incorrect statement carelessly or knowingly made, or any other thing carelessly or knowingly done that is inconsistent. But how is 'good faith' and intent to be proven? Section 24 appears to totally undermine any safeguards supposedly provided by the requirements to follow the statutorily-defined processes contained in the Bill.

It is not just the undermining or inadequacy of any such safeguards but their inadequacy in the first place. Indeed, there is scope for abuse for which the perpetrators should be held criminally and/ or civilly liable that the Bill has not even identified, let alone provided safeguards against. This primarily concerns the fact that there are parties not directly involved in carrying out the process who could nonetheless stand to gain by a person's death and who could take action towards that goal by exerting influence over that person or others who are directly involved in carrying out the process. It should therefore be possible to bring prosecutions against any such perpetrators.

- 4. The Bill outlines a three stage declaration and request process that would be required to be followed by an individual seeking assisted suicide. Do you have any comment on the process being proposed?**

Cancellation process – needs clear explanation that earlier stages are not de facto cancelled by the cancellation of later stages

- 5. Do you have any comment on the provisions requiring that the person seeking assisted suicide must have a terminal or life-shortening illness, or a progressive condition which is either terminal or life-shortening?**

As argued in the main submission, while it may have been intended to distinguish a particular group of people from the wider population of disabled people these provisions fail to do so. They also fail to account for the many other factors than impairment that have a profound impact on the quality of life of people who would be covered by these provisions.

According to the Policy Memorandum accompanying the Bill ‘They may be paralysed or have limited mobility, they may need help with feeding and washing, everything they do may be painful, slow and frustrating.’ (paragraph 4). They may indeed experience all of these things and, with the right support, removal of barriers, and so on, experience very little if any deterioration in quality of life. The fact that this statement is even included in the Policy Memorandum demonstrates a profound misunderstanding of the impact of impairment, and the fact that having choice and control over the support provided with such tasks (who, how, how much, etc) means that requiring assistance is in no way incompatible with preserving dignity and autonomy.

In fact, it is not just targeted at disabled people. Paragraph 5 of the Policy Memorandum states: ‘It is also aimed at those whose diagnosis has allowed them to see such a situation in prospect, and even those who are currently healthy but fear for an uncertain future.’ This risks pandering to and reinforcing fear of disability (or rather an undignified life due to external factors) among the general populace.

If it is the intention to single out people for whom the impact of impairment is overwhelmingly intolerable regardless of the availability of appropriate support to adjust to a newly acquired impairment and/ or to live a good life with one, removal of barriers and/ or stigma associated with impairment, absence of indirect pressures, etc, there is a very long way to go – not least because those factors remain unaddressed and, in the case of indirect pressures, near impossible to ascertain.

- 6. Are you satisfied with the eligibility requirements as regards age, capacity, and connection with Scotland as set out in the Bill? No comment.**

7. Do you have any comment on the roles of medical practitioners and pharmacists as provided for in the Bill?

We have some concerns regarding the assumption that medical professionals will necessarily be well-placed to make pronouncements on a person's quality of life. While they may indeed be the right people to give a medical diagnosis and prognosis, as argued in the main submission those do not neatly and consistently relate to quality of life. There are many external factors that play a critical role. Yet, in view of their professional focus on impairment it would be understandable if they, more than others, would take a narrow view on the relationship between medical condition and quality of life. We are aware of instances where doctors have issued 'do not resuscitate' notices to patients with impairments, without consulting them or their families, simply based on the practitioners own prejudice and misplaced assumptions as to the persons poor quality of life and lack of desire to continue it.

The fact that two different members of the medical profession must be involved also requires some examination. If the intention is to ensure that each is completely independent of the other in their assessment, which would presumably strengthen the supposed safeguard, it is necessary to consider the relationship between the two: the potential difficulties created by disagreement between colleagues for any ongoing professional relationship, and scope for like-minded colleagues to be rapidly identified and for referrals to be channelled to them.

There is also the critically important matter of principle and of the human right 'to life'. Everyone must be able to trust that their doctors is there to promote their good health and that the National Health Service should not be transformed into a National Death Service.

Of course, none of this is not to assert that all members of the medical profession will take a negative or narrow view of impairment. It is, though, to suggest that the fact of the involvement of members of the medical profession cannot be taken to indicate that robust safeguards are in place.

8. Do you have any comment on the means by which a person would be permitted to end his/her life under the Bill? No comment.

9. Do you have any comment on the role of licensed facilitators as provided for in the Bill?

Our main concern here is the outsourcing of the role of licensed facilitators and of trainers. Clearly it will be important to ensure that no perverse incentives enter the equation, for example, so that payment is contingent on the number of deaths 'facilitated'.

10. Do you have any comment on the role of the police as provided for in the Bill?

In view of the lack of transparency throughout the process, the scope for a decision to pursue assisted suicide to be compelled through the exertion of a variety of indirect pressures, and the significant watering down of the need to follow the statutory requirements of the process, including the impossibility of ascertaining whether failure to do so emanated from good or bad faith (section 24), it is hard to see how the police could begin to identify illegal action or construct a robust case against the perpetrators. If there are few prosecutions in places where assisted suicide is legal (e.g. Oregon), it seems highly plausible that it should be for these reasons, rather than providing testimony to the absence of abuse.

11. Do you have any comment to make about the Bill not already covered by your answers to the questions above?

The inadequacy of safeguards would benefit from further elaboration. Aside from those already mentioned in the mains submission and in this annex, concerns include:

- Relatives who stand to gain may not be directly involved in carrying out the process but they are nonetheless able to exert powerful influence. Given the closed nature of such relationships this could be near impossible to detect. But reasons why a person might confirm no undue influence when there has in fact been undue influence include threats/ fear of mistreatment/ powerlessness and being made to feel like a burden. Of course a person might also believe they are a burden despite relatives' reassurance that they are not.
- Scope for institutional gain – Governments who wish to save public money to fund tax cuts, local authorities/ health authorities who could save expenditure on expensive care provision, corporate (private or voluntary sector) gain when payment is contingent on numbers. Safeguards also need to provide protection from all of these.
- The difficulties of identifying euthanasia and direct killing in what is a far from transparent process.